

---

# The Death of an Innocent

Larry Fontanilla Jr, MS-II  
John A. Burns School of Medicine

It is ironic that moments which hold the promise for life's greatest joys, necessarily hold a similar capacity to become our most devastating sorrows. Call it cosmic irony, the flip side of the coin, or balance of yin and yang, it is the tragedy which inspires art and the real substance of our lives' experiences. Take for example that you are an expecting parent.

Think of it, the day of your child's birth. For nine months, you have been anticipating this day; perhaps imagined this very moment. For nine months, you have been through morning sickness, cravings, weight gain, lower back pain, incontinence, and fetal Tae Kwon Do (as mother or father). For nine months, you have begun dreaming for your child... blonde or brunette, poet or physician, birthdays, graduations, and christenings. And for weeks now, you've felt that strange mix of nervous, gut-wrenching anxiety coupled with an ebullient expectancy for the sheer joy, that's just around the corner. Then the moment arrives, and thus begins the chaotic rush, which you know you won't ever be able to fully recall, but which you also know, you'll never forget. But wait... isn't this taking a little long? What did that nurse just say? What was that? ...a little girl? ...but, -wait, wait, where are you taking her? Wait, what did you just say? What's wrong?

The doctor has quietly come out and explained, "...your wife has given birth to a six pound baby girl. However, there are problems. Your wife is fine, and you can go in and see her as soon as we are done. However, your daughter is in the neonatal intensive care unit. As far as we can tell at this time, she has a condition known as hypoplastic left heart syndrome. It is lethal, if left untreated. Weren't you made aware of this by your obstetrician? -Oh, you're Jehovah's witness."

And there, the worst moment of your life just got worse. You see, the only chance your new child has for life, are a series of surgeries known as the Norwood procedure, or a complete heart transplant... both of which will never be performed without a blood transfusion. Yet, this is just not an option. It cannot be. Not for you. Not as a Jehovah witness.

Now, try a change in perspective. What would you do here as a physician? Would you seek a court order, and have the child treated? Or would you leave the decision to the parents, well knowing that this may mean death for the newborn?

However, before you make your decision, you should know a few unique points about this scenario. First, the Norwood procedure, which may partially repair the child's heart and prolong her life, is by no means curative. Also, because of the issues surrounding transfusion, the doctors may not place the child on the waiting list for a heart transplant. The likely legal delays could very well keep the heart from another needy child. Lastly, both the Norwood procedure and the heart transplant carry high mortality rates. Therefore, probability indicates that there will be little difference in outcome between treatment and non-treatment. After nasty legal maneuvers, a healthy trampling of the constitution, and amidst all of the emotion and turmoil on both sides, the child will most likely die. Now then, what should you do?

Why pose this question, some ask? Why such a detailed and specific scenario? Isn't it so complex and hypothetical that the discussion is moot? In actuality, this scenario is not hypothetical at all, but occurred this year in Irving, Texas. The surgeons in charge decided to leave the decision for treatment in the hands of the parents, and no court order was sought. In a statement from the University of Texas Southwestern Medical Center at Dallas, the surgeons explained, "whether treated or not, (her condition) has a high mortality risk and has little chance of a cure...In cases with such a grave prognosis, where non-treatment is a reasonable option, we believe the decision to pursue treatment is best made by the families involved" (Young, 1996, A8). Valerie Marie Hernandez died on January 25, 1997.

There is also another reason to discuss this case in specific, and it is because it is unique. The very complexity which makes the case nearly moot, makes it difficult to cite standard decisions, and forces the doctors to make an ethical choice of their own. Cases that are black and white are both less common and of less personal interest. It is what we choose, less as a profession, but more as an individual that will define the doctors that we are or will become. It is the decision we make: with the 72 year old, with only a tendency to wander, refusing treatment; with the 61 year old couple seeking in vitro fertilization with an egg donor; with a colleague you've witnessed perform some type of professional indiscretion; or something as little as making a sexual history a standard part of your work up, regardless of comfort level.

In this case, the chance for a child's life is weighed against parental rights and freedom of religion. In cases similar to this, where treatment is assured to benefit the child, the solution seems time tested. Typically, a family court issues an order taking custody away from the parents, and placing the child in protective services. Once this is established, by order of the court, the child will receive the medical procedures deemed necessary, and within the best interest of the child. After recovery, the situation is reevaluated and the child may be returned to the parents' care.

However in this case, what exactly is the best interest of the child? It is not as simple as choosing life or death. Instead, the choice lies between two courses of action which probability determines will end with the same result... death of the infant. In such a situation then what makes anyone's opinion anymore justifiable than that of the child's own parents. Wouldn't it be simpler for all, to allow these parents what little time they might have with their child, free from legal, religious, and medical battles? (But then again, what's simple, is rarely what's "right.")

Still, isn't a chance at life better than assured death? If there were only a one percent chance of survival with the proper medical treatment (Norwood palliation followed with subsequent transplant), wouldn't that 1 in a 100 chance be worth taking for this child's life? If not, would two percent be enough? How about five? Ten? How high would the success rate have to climb for us to take action on behalf of this innocent, this patient, who is unable to take any action for herself? It is a serious question, which everyone

involved must come to answer on their own.

Say that a court order was obtained, and that the best case scenario ensued. Who stands to gain?

Some might say the parents, simply because they have a daughter, where they might have lost her. However, after they've gone through the hurt and pain of having a child diagnosed with a lethal disease, they then lose custody of that child to the state. Furthermore, the state and the hospital proceed to violate that child and essentially damn her in the life hereafter. For the rest of their lives, they'll live with that knowledge, and in some sense guilt. And after all is said and done, it is questionable whether they can get their daughter back. Have they gained? Not in their eyes.

The daughter then, surely has gained. She is alive. Yes, but she will always live with two hard facts. First, should she grow and adopt her parents' religion, she will live her life with the knowledge that she is damned in the afterlife, through no fault of her own. Furthermore, (despite how piously she may live) there is nothing she will ever be able to do to remedy that. Secondly, regardless of what religion she may adopt, she will have to live with the knowledge that her parents were willing to allow her to die. There aren't many who can imagine the horrific ramifications that might entail, nor should anyone have to. Aside from these facts, she will probably wrestle with a host of issues including alienation, isolation, and poor self-body image. This all rests on the assumption that she is returned to her parents and does not become a ward of the state. Has she gained? Surely, this is difficult to say.

The state, perhaps it has gained. It has won the battle and saved the life of this child, too helpless to defend herself. However, it had to overcome two significant freedoms in order to do this. First, it berated (at the least) the freedom of religion. These parents believed that their child's mortal life was worth the sacrifice, if the alternative meant eternal damnation. Of course, a lengthy theological debate could ensue, but the issue at stake here is not whether the belief is "right," but whether the parents have the right to this belief. For the court order to be issued, someone outside of this family said that this belief or value is wrong or unfounded, probably just because they do not share it. Surely, the court would deny this. However, how else can one sensibly respect such a religious belief (as is guaranteed by the Constitution) and still act against the parents?

One might answer that the child did not have the chance to choose this religion. How can it be assumed that she would hold the same belief? This brings up the second right temporarily overlooked by the court system, parental rights. Should the state ever have a say in the choices that parents may make for their children? If a parent's choices are not in the best interest of the child, then the state must protect that child from the parent. Clearly, this holds true for obvious instances of abuse or neglect. However, aren't Valerie's parents trying to make the best possible choice for their child? I suggest that if the state is allowed to intervene here, logical progression of such a stance may include the state garnishing a family's wages to pay for orthodontics that it deems "in the best interest of the child." Else, it may take children away from poorer families and place them with richer families, if it considers that "in the best interest of the child." Furthermore, most drastically, for the sake of the children, the state might mandate who may and may not have children. These hyperboles may seem ridiculous, but they do illustrate the difficulty in assessing whether parents' rights to speak and act for their children should be overridden. Has the state gained then? It could be said so, but only at the expense of two pillars of its foundation.

The medical community, then, must have gained. This finally might be true. Another life has been saved. The statistics for the procedures and for the surgeons have risen. The medical center gains positive publicity for its dedication to a helpless, desperate

infant. And laurels, respect, and new business are rolling in from around the country. All they needed to sacrifice was the enlarged divide between the medical community and a minority religion. It is not unreasonable to say that actions like the proposed court order may keep future patients away. They may elect to seek alternative treatments, or faith healing (which would not damn their souls), rather than turn to an institution which they know will not honor their own beliefs and values. However, let's neglect this hypothetical outcome for a moment to assess the status of the medical community. Yes, it has gained, but is this reason enough to put all other parties through their torments?

Recall also that this was a best case scenario. In all likelihood, in the midst of the battles and emotions, the personal struggles and pain, little Valerie would remain as dead as if she were left in peace.

It is my opinion then, that the doctors at the University of Texas Southwestern Medical Center at Dallas made the proper decision in not seeking a court order, for a number of reasons. First and foremost, since the prognosis of treatment and non-treatment are so similar, in cases without religion as an issue, many institutions leave the decision in the hands of the parents. There should be no reason to change this attitude simply because of a family's religion. Next, there are the pain and lifelong struggles with personal and religious issues that would plague both parents and child. Yes, the child may live, but at what cost to them? Third, in order to obtain a court order, significant civil rights must be violated. These issues themselves are not without ramifications. Lastly, such a court order could only further divide the chasm growing between the medical community and certain religious groups. It is a difficult question, but is this one case, worth the many other future cases that would never arrive at our attention, because of a Jehovah's witness' fear of being violated by our values and protocols, and not their own? It is sad, and it is difficult, but perhaps, the only ethical thing to do is to honor the parents' religion and choice, even if it means the death of an innocent.

## References

1. Young, M. Religious belief vs. a child's life. *The Tacoma News Tribune*. (1996, December 22); p. A8.
2. Bando K., Turrentine M, Sun K, Sharp T, et. al. Surgical management of hypoplastic left heart syndrome. *Annals of Thoracic Surgery*. 1996; 62: 70-77.
3. Curtin, L. Parental rights: who pays the price? *Nursing Management*. 1992; 23: 26-30.
4. Gulgesel H., Massaro T. Management of hypoplastic left heart syndrome in a consortium of university hospitals. *American Journal of Cardiology*. 1995; 76: 809-811.
5. Morris C., Outcalt J., Menashe V. Hypoplastic left heart syndrome: natural history in a geographically defined population. *Pediatrics*. 1990; 85: 977-982

## Healthful Eating

American Heart Association  
Fighting Heart Disease and Stroke

*Fruits and vegetables are important components of a healthful diet. Here's why:*

- They are easy to fix and serve
- There are so many choices
- They are the original "fast food"
- They taste great
- They are good for your health

©1996, American Heart Association

